Received 15 July 2013
Revised 12 February 2014
Accepted 17 February 2014

Match between needs and services for participation of older adults receiving home care

Appraisals and challenges

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Abstract

Purpose – This paper aims to explore the match between needs and services related to participation for frail older adults receiving home care.

Design/methodology/approach – A qualitative multiple case study was conducted with 11 triads each involving an elder, a caregiver and a healthcare provider working in a Health and Social Services Centers (HSSCs).

This study was financed by the Réseau québécois de recherche sur le vieillissement and the Université de Sherbrooke. Thanks to Annie Carrier, Mélanie Couture and Frances Gallagher for their comments and suggestions that helped to improve the interview guide and advance this study. Thanks to research assistants Joanie Lacasse-Bédard, Anaïs Marcil-Héguy, Eugénie Cadieux-Pinsonnault and Annie-Ève Jutras, who contributed to the feasibility of this major research project. The advice given by Jean-Philippe Viriot-Durandal, coordinator of the special edition of 'Pouvoir gris', and Pascal Dreyer, Editor-in-Chief of Gérontologie et société, was much appreciated. Thanks to the HSSC for its help during the recruitment process, and especially to the healthcare providers who participated in the interviews. Finally, thanks to the older adults and their caregivers who agreed to participate in this study, gave their time and expressed their needs regarding their social participation.

Leadership in Health Services
Vol. 27 No. 3, 2014
pp. 204-223

1751-1879
DOI 10.1108/LHS-07-2013-0030

Findings – Although HSSCs in Québec are supposed to promote social integration and participation of older adults, services provided to the older adults in this study focused mainly on safety and independence in personal care, dressing, mobility and nutrition, without fully meeting older adults' needs in these areas. Discrepancies between needs and services may be attributable to the assessment not covering all the dimensions of social participation or accurately identifying older adults' complex needs; older adults' and their caregivers' difficulties identifying their needs and accepting their limitations and the assistance offered; healthcare providers' limited knowledge and time to comprehensively assess needs and provide services; guidelines restricting the types and quantity of services to be supplied; and limited knowledge of older adults, caregivers and healthcare providers about services and resources available in the community.

Originality/value – To improve and maintain older adults' participation, a more thorough assessment of their participation, especially in social activities, is required, as is greater support for older adults and their families in using available community resources. It is also important to review the services provided by HSSCs and to optimize partnerships with community organizations.

Keywords Health services, Conformity of services, Elder care, Met needs, Participation needs, Participation services

Paper type Research paper

Background

Optimizing the participation of frail older adults can help them remain in their home longer and integrate better into their community and society, and have a positive impact on their physical and mental health. According to the Disability Creation Process (Fougeyrollas *et al.*, 1998) as well as a scoping review of definitions and analysis of social activities (Levasseur *et al.*, 2010), participation corresponds to the accomplishment of daily activities (nutrition, fitness, personal care, communication, housing and mobility) and social activities (responsibilities, interpersonal relationships, community life, education, work and leisure) valued by the person and his/her sociocultural context (Appendix). Varying on a continuum ranging from a situation of optimal participation to a situation of handicap, participation is the result of a two-way interaction between a person's characteristics (personal factors) and context of life (environmental factors). For older adults, participation in social activities contributes to having more positive perceptions of their health (Young and Glasgow, 1998), decreasing the consequences of aging and delaying signs of loss of autonomy (Mendes de Leon *et al.*, 1996), and increasing their quality of life (Levasseur *et al.*, 2008).

Various interventions can improve the participation of frail older adults and ultimately their power to change themselves and their environment as well as their quality of life. These interventions can be formal (e.g. psychosocial interventions; home adaptations; rehabilitation) and informal (e.g. volunteers' friendly visits). They can be offered by various resources, such as healthcare professionals and social services, community organizations, volunteers and family members who support older adults living at home (Cardinal *et al.*, 2008). These interventions include actions and services related to assessment, treatment and rehabilitation, as well as psychological and social support (Caron and Ducharme, 2007).

To increase participation of older adults, it is possible to improve the physical, cognitive and psychological capacities of older adults (e.g. empowerment; tolerance in task effort; task planning; self-respect; ability to maintain and create social links), to transform the environment so that it is adapted and safe (e.g. accessibility of the house in a wheelchair, social conditions), or to modify daily and social activities to facilitate

their accomplishment (e.g. adapt a leisure activity so that it is carried out in a seated position rather than standing up). For example, group exercise programs and support groups led by peers and professionals have been shown to be effective in reducing social isolation and solitude (Desrosiers *et al.*, 2007). To enable older adults to remain at home, health services must commonly involve promotion of autonomy, independence and social connectedness (Parsons and Parsons, 2012). It is important, however, to offer healthcare services that are compatible with the individual' aspirations and health. Following principles of motivational and client-centered approaches, active involvement of older adults and their families in the goal-setting process is required to ensure a much broader and integrated approach including family matters, psychosocial needs and other opportunities available in the community (Parsons and Parsons, 2012).

In response to individual interaction difficulties or challenges to modify individual environments to facilitate the participation of older adults, a number of population health initiatives have focused on environmental factors. The Global Network of Age-friendly Cities, an important initiative of the World Health Organization (WHO, 2007), promotes the importance of meeting the needs and supporting older adults' participation, whatever their level of functional independence. This initiative encourages the development of accessible community environments that promote safety, mobility and flexible and affordable means of transportation. The importance of access to information regarding activities and existing services and the need to integrate various activities that are adapted to the person's capacities are also addressed by this initiative. The WHO (2007) has reported that older adults participate actively in their community life but are disappointed that the opportunities are not numerous, not varied and not nearby. The main problems are accessibility and costs, as well as the quality of information about existing activities. Concerted efforts to motivate and encourage older adults to participate could make a difference between optimal participation and social isolation.

With respect to individual interventions, to facilitate the participation of frail older adults, three main types of resources are presently used in Quebec:

(1) the contribution of caregivers;

(2) home care which includes in-home and day center services provided by Health and Social Services Centers (HSSCs); and

(3) community organizations and social enterprises (Dechêne *et al.*, 2007).

In Quebec, enabling older adults to remain longer in their homes is a social and political choice which first directly concerns caregivers, who are essentially members of the family (Ducharme, 2006) and the main support system (Caron and Ducharme, 2007). Caregivers provide approximately 90 per cent of the services involving assistance and care to older adults (Hébert *et al.*, 1997). Moreover, home care program covers the main primary care services designed to enable frail older adults to remain in their home. This program coordinates some of the services offered to older adults (assistance with personal care; nursing, social work or occupational therapy; community organization, etc.; Appendix), while taking into account the person's specific situation, needs, physical and social environment (MSSS, 2003). Finally, this program collaborates with community organizations and social enterprises, which offer a wide range of services and activities (Appendix). Community organizations have various functions, such as to:

- encourage social contacts and reduce social isolation;
- promote rights and advocacy; and
- improve older adults' quality of life and living conditions.

In spite of the existence of these interventions and resources, their fit with the participation needs of frail older adults is limited. It has been demonstrated that resources need to be improved and developed to optimally meet the numerous complex and heterogeneous needs of frail older adults and to prevent caregiver burnout (Ducharme, 2006). With population aging, Quebec will have to, on the one hand, revise the organization of long-term care by increasing services offered in the community and, on the other hand, widen the range of services covered by the public sector (Choinière, 2010). A study conducted among users ($n = 8{,}434$) of home care services in one region of Quebec demonstrated that only 8 per cent of the needs related to daily activities were met (Tousignant *et al.*, 2007), yet improving interventions related to the accomplishment of daily activities of frail older adults is an important target of the HSSCs' action plan.

In addition, these primary health and social care establishments have a responsibility to the population in their area to meet their needs for social activities (socialization and leisure), and to work with partners in the local area network, including community organizations. Therefore, they are not only responsible for caring for and guiding their clients through the healthcare system, they also need to actively ensure that efforts are made to maintain and improve the health and well-being of the population in their area (MSSS, 2004). However, it has been documented that although psychological needs, such as emotional support while adapting to new health problems, were considered a service priority, they were not met satisfactorily for older adults who had had a stroke and their caregivers (Talbot *et al.*, 2004). Additionally, while services that aim to modify the physical environment are usually accessible, services to meet psychological and cognitive needs and support participation are scarce (Markle-Reid *et al.*, 2008). Furthermore, tools for evaluating the needs of frail older adults contain few psychosocial elements (Delli-Colli *et al.*, 2007). In the absence of sufficient documentation of these psychosocial aspects, healthcare providers cannot develop an intervention plan or allocate services according to the real psychosocial needs and thus fully enhance their clients' quality of life.

In summary, a consensus exists regarding the importance of enabling the participation of frail older adults. Clinical knowledge and empirical data, however, demonstrate that the majority of the interventions offered by primary HSSCs mainly focus on daily activities to the detriment of social activities. Moreover, the interventions offered by HSSCs have been shown to be partial, fragmented and insufficient in quantity. In addition, very few studies have documented the interventions offered by community organizations and caregivers to optimize the participation of frail older adults. An in-depth exploration of needs and interventions to enable participation as perceived by the main stakeholders concerned by this issue, i.e. healthcare providers in home care programs, older adults and their main caregivers, is therefore necessary. To our knowledge, no study has documented the match between needs and existing interventions, and explained the challenges to attain this match. This study aimed at investigating the match between needs and interventions for participation, i.e. accomplishment of daily and social activities, of older adults presenting a loss of

autonomy who receive services from a home care program. More specifically, the study aimed at identifying:

- the participation needs of older adults;
- interventions enabling participation offered by caregivers and healthcare professionals; and
- the match between needs and interventions.

Methods

Research design and participants

This study was conducted using a qualitative multiple case study design, which allows analysis and in-depth description of a social phenomenon (Yin, 2009). Data were collected from January 2011 to February 2012 with 11 triads involving three types of participants linked together:

(1) frail older adults aged 65 years and older receiving home care services from an HSSC in the province of Quebec ($n = 11$);

(2) caregivers ($n = 11$); and

(3) healthcare providers in an HSSC home care program ($n = 10$) and the mental health sector of the same HSSC ($n = 1$).

In Canada, to the extent allowed by human, material and financial resources, each province is responsible for organizing the delivery of universal and free-access healthcare services to its population (Act Respecting Health Services and Social Services, LSSSS, 2014). Similar to the American Medicare and Medicaid programs (Richmond and Fein, 2005), the Canadian healthcare system is mainly financed through tax revenues. The HSSC is a local authority, which is a multivocational institution operating a local community service center, a residential and long-term care center and, where applicable, a general and specialized hospital center. The mission of the HSSC is to improve the health and well-being of individuals by offering accessible, integrated, continuous and high-quality services. It also implements preventive and community-wide measures with its local partners. In this study, the HSSC involved 2,800 employees, 125 doctors, 100 researchers and 450 volunteers.

To be eligible, participants had to understand and speak French. In addition, older participants had to:

- have a score of 15 or more on the Functional Autonomy Measurement System (SMAF), considered to indicate a moderate to severe loss of autonomy;
- live in a conventional home or a residential home for independent or semi-independent older adults;
- receive home care services from an HSSC; and
- have a caregiver interested in participating.

Older adults unable to consent, presenting significant difficulties in communication or in palliative care were excluded. Caregiver participants had to regularly care for their older participant, while healthcare providers had to be the main clinician working with the older participants at the time of the study or have been actively involved in the provision of services in the previous six months.

Data collection

For each of the 11 triads, semi-structured interviews lasting between 60 and 90 minutes were conducted separately with the older adult, their caregiver and their main healthcare provider, using a semi-structured interview guide. Questions included for example:

> Tell me about the things you usually do in a typical day. Tell me about your social activities in the community, i.e. outside your home. What are your requirements in connection with your activities? What help do you receive to carry out your activities, what resources do you use to conduct your affairs?

A follow-up telephone interview was done when needed to clarify information. Sociodemographic characteristics were also collected for each participant, and older adults' clinical records at the HSSC were reviewed with a data extraction grid. Interview guides and the data extraction grid contained in the older adults' files were reviewed by an external group of experts in qualitative research and were adjusted during data collection (Gauthier, 2004). All interviews were audiotaped and transcribed. Multiple sources of information were used to perform data triangulation and promote a holistic understanding of the situation. The HSSC Ethics Research Committee approved this study.

Data analysis

The participants' sociodemographic characteristics were described by means and standard deviations, or frequencies and percentages according to the type of variable (continuous or categorical, respectively), or preferred presentations of the variables. Such description allowed contextualizing the study and its results. A thematic content analysis as described by Miles and Huberman (2003) and Yin (2009) was performed using a coding guide based on the interview guides and data extraction grids. Themes emerged from the content of the interviews and were only afterwards organized and renamed according to the underlying grid. Interviews and older adults' clinical records for each triad were analyzed individually (intracase analysis) and syntheses were written following analyses of each triad. Intercase analyses were then performed to identify similarities and differences across cases. The triads were counter-coded by two researchers (M.L. and N.L.). Additional memos including thoughts, questions and discussions of the research team were used. Analyses were supported with the QSR N′Vivo (version 9.0) software.

Results

Older participants (O) included five women and six men aged between 66 and 88 years. In this sample, five participants had physical disabilities, five had mild cognitive impairments and one had a mental illness (Table I). The majority lived at home, were married, had 11 or less years of education and rated their health as good. The caregivers (C) included nine women and two men aged 55-90 years, including six spouses who were mostly retired and who rated their health as excellent (Table I). Healthcare providers (H) were mostly women, with 15-16 years of education and 4-32 years of clinical experience with older adults (Table II). In addition to having been or currently being supported by a home healthcare provider or a mental healthcare provider, four older adults received help with bathing, three went to a day center and two benefited from a voucher program (direct allocation for personal assistance services or long-term domestic help at home).

Table I.
Characteristics of older participants (n = 11) and their caregiver participants (n = 11)

	Age (years)	Gender	Education	Marital status	Living situation	Self-rated health	Type of residence	Income	Diagnoses	SMAF	Type of disability	Relationship with older adult	Professional status
Older adults													
O01	88	F	C	M	C	P	P	D	MC	49.5	P		
O02	83	M	C	M	C,F	B	P	4	NV	29.5	P		
O03	78	F	S	D	S	B	L	D	SEP	44.5	P		
O04	78	M	P	M	C	P	P	2	MP	26	P		
O05	85	F	P	V	S	P	L	3	MC	19.5	P		
O06	69	M	S	C	R	E	R	5	TB	19.5	S		
O07	70	M	S	M	C	B	P	D	P	35.5	C		
O08	66	M	M	M	C	B	P	6	P	41	C		
O09	72	F	C	D	S	B	L	D	TM	26.5	C		
O10	81	M	S	M	C	B	P	5	P	36.5	C		
O11	87	F	P	M	C	M	R	3	MC	25.5	C		
Caregivers													
C01	90	M	S	M	C	E						C	R
C02	84	F	B	M	C,F	B						C	R
C03	58	F	C	D	S	E						E	TA
C04	78	F	P	M	C	P						C	R
C05	62	F	S	D	S	E						E	C
C06	56	F	S	M	C	E						R	TP
C07	65	F	S	M	C	B						C	R
C08	66	F	B	M	C	E						C	R
C09	77	F	C	V	S	B						F	R
C10	81	F	S	M	C	B						C	R
C11	55	M	M	M	C	P						E	R

Notes: Gender: F: female, M: male; education: p: elementary (1-6 years), s: high school (7-11 years), C: college/trades (12-14 years), B: bachelor's degree (15-16 years), M: master's degree/doctorate (> 17 years); marital status: M: married/common-law, V: widow, C: single, D: divorced/separated; living situations: living alone, C: in couple, F: with a family member; self-rated health: E: excellent, B: good, P: fair, M: poor; type of residence: P: owner, l: tenant, R: residence for independent or semi-independent older adults; income: 1: $0-10,000, 2: $10,001-15,000, 3: $15,001-20,000, 4: $20,001-25,000, 5: $25,001-40,000, 6: > $40,001, D: missing data; diagnoses: mc: cardiovascular disease, NV: blind, sep: multiple sclerosis, MP: asthma and chronic obstructive pulmonary disease, TB: bipolar disorder, P: Parkinson's, TM: musculoskeletal disorders; SMAF: functional autonomy measurement system (/87); type of disability: P: physical, S: mental health problem, C: cognitive problem; relationship with older adult: C: spouse, E: child, M: other family member, R: person responsible for the residence; professional status: TP: full-time worker, TA: part-time worker, C: unemployed, R: retired

Continuous variables	Mean (SD)	Median (interquartile range)
Age (years)	44.5 (6.9)	44 (3)
Experience with older adults (years)	17.8 (9.4)	18 (5.5)
Experience in current workplace (years)	12.2 (9.6)	8 (3)
Categorical variables	Frequency (per cent)	
Gender (woman)	7 (63.6)	
Education		
College/professional degree (12-14 years)	2 (18.2)	
Bachelor's (15-16 years)	7 (63.6)	
Master's/PhD (>17 years)	2 (18.2)	
Professional title		
Occupational therapist	1 (9.1)	
Case manager	4 (36.4)	
Respiratory therapist	1 (9.1)	
Nurse	2 (18.2)	
Medical doctor	1 (9.1)	
Social worker	2 (18.2)	

Table II. Characteristics of healthcare provider participants ($n = 11$)

Findings regarding the match between needs and interventions enabling participation

Services for frail older adults currently available from home healthcare providers focused on urgent basic needs related to home safety and functional independence (Table III):

> She is clean, she doesn't smell, she doesn't look neglected. […] I'd say that her needs are met. Always make the nuance between 'needs' and 'desires'. According to my observations, home maintenance is safe (H03).

In addition, the majority of health services provided aimed at independence in bathing, dressing, nutrition and mobility, "We go every morning to help her get up and prepare for the day" (H01). However, even for these dimensions, the HSSC's limited resources could not fully meet the needs of the majority of the older participants, especially for personal care. "They give me a bath a week, I don't think it's enough. I would like to have two. I'm not a demanding person" (O01; Table I). Guidelines regarding help for hygiene were clearly established by the HSSC, but the supply did not meet demand, creating a waiting list:

> She (wife) called me to ask for a second bath (per week) because her husband might be a little more incontinent. He'll be on a waiting list […] unless he is very incontinent (H04).

In addition, the majority of the older participants had unmet needs, primarily in social activities (responsibilities, interpersonal relationships, community life and leisure) and in daily activities (fitness, housing and mobility). Subsequently, older adults tended to resign themselves to their situation, did not ask or waited a long time for help, preferring to be aided by family members, did not leave home often and reduced their social network and activities:

> I don't need it because I'm not able to go anywhere. I don't fit into a group because I don't know how I will react. I used to be in groups (O03).

Findings regarding the *match* between needs and interventions enabling participation
Interventions mainly addressed urgent needs related to safety at home and daily activities, but still did not fully meet these needs
The majority of older adults had needs that were unmet, especially for social activities (responsibilities, interpersonal relationships, community life and leisure), and some daily activities (fitness, housing and mobility outside the home)
Challenges of an optimal *assessment* of participation needs
Assessments did not fully cover all dimensions of participation, or identify sometimes complex needs, taking into account what was reported not only by the older adults but also by their caregivers, and also what the older adults were actually capable of doing versus what they did or would like to do. Thus there was a discrepancy between the needs perceived by the older adults, family caregivers and healthcare providers in some cases, primarily but not exclusively when the older adult had cognitive impairments or when the caregiver was less involved
Older adults and their caregivers had varying and sometimes limited *empowerment* and ability to identify their needs, especially when they had cognitive impairments, but also when they had physical disabilities, experiences, previous habits or special aspirations that influenced their needs, and varying and sometimes limited acknowledgment and acceptance of the older adult's disabilities
Healthcare providers had: limited knowledge of the older adults and caregivers they served, limited theoretical and practical knowledge about the dimensions and assessment of participation, and limited time available to thoroughly assess needs
Challenges of providing optimal *interventions* to meet participation needs
The interventions provided were in limited amounts, mainly involving home care services from the HSSC governed by guidelines (e.g. assistance with hygiene once a week), were in environments where accessibility varied and was sometimes limited, partially met the older adults' needs, with activities being only partially adapted to the older adults' abilities, and involving costs and varying availability of caregivers, and were offered mainly to the older adults while the caregivers also had needs they identified in order to be able to continue to meet the older adults' needs
Older adults and their caregivers had varying and limited *empowerment* and knowledge about interventions available in the community, had limited financial resources they could use for environmental adaptations, paid services and technical aids, distrusted the use of services outside the public system, had varying and sometimes limited willingness to listen to the healthcare providers' recommendations including assistance, and had varying and sometimes reduced satisfaction with some currently available interventions
Healthcare providers had limited knowledge of interventions available in the community including the procedures to access these interventions, and limited time available to implement interventions to meet all the older adults' needs, including supporting them and their caregivers in adapting to disabilities and assistance, or to take steps to use community services

Table III.
Summary of results

Challenges of optimal evaluation of participation needs

Several challenges related to the needs assessment may explain this discrepancy (Table III). First, the assessments made by the HSSC only partially covered the dimensions of participation and did not determine in depth the complex needs of older adults. "I didn't ask. Often I (ask) if it's okay like that? But I did not discuss the matter any further" (H05). Healthcare providers sometimes concluded quickly if the person required services or not, as mentioned in three of the triads. "Says she's in a good mood and happy at home. Not bored. Says that she's good and doesn't need anything more. No additional service requested" (notes in file 09). Specifically, most healthcare providers did not explore some daily activities and current and desired social activities, including interpersonal relationships:

> There's his daughter. I think they cannot see each other often, but it is vague in my mind if he would like to see her more often. I don't know if he sees friends, if they regularly have guests, I don't know (H04).

Despite the limited time available, however, some healthcare providers wanted to improve their practices. "Based on all the questions you have asked me, it's giving me ideas for future evaluations in which I could perhaps strengthen my questions" (H05).

In addition, older adults and their caregivers sometimes had difficulty recognizing and accepting their disabilities and identifying needs that were occasionally complex: "He says he wants to go out more, but when he is offered opportunities, he says: I won't because I have a problem with my stools (fecal incontinence)" (H03). Some older adults also had difficulty asking for help, for example when eating meals: "I do need but I don't dare ask" (O01; Table I). Finally, there may be a discrepancy between the perceived needs of the older adult, family caregiver and healthcare provider, especially when the older adult has a cognitive impairment: "She often reported that everything went well when she presented several challenges and she put herself at risk of falling several times" (notes in file 11). A difference of opinion was sometimes noted between the older adult and the caregiver:

> The couple disagrees about the need for home care services. The husband is rarely satisfied and therefore gives up after trying the services. In face-to-face interviews, the wife recognizes more needs […] (notes in file 11).

Challenges of offering optimal interventions to meet needs for participation

Other findings related to interventions help to explain the discrepancy between needs and interventions enabling participation (Table III). First, as already mentioned, despite growing demand, HSSC healthcare services are limited and governed by guidelines. In agreement with organizational vision and guidelines, limited help can be provided. For example, personal hygiene can only be provided once a week: "In previous years, there were plenty of things that were put in place, but it seems that over time, there is also less budget for services" (H05). In addition, compared to home healthcare providers, the mental healthcare provider seemed to help his client more regularly and provided tools for him:

> I saw him once a month. I worked more to restore his confidence, get him to express what he really wants as an intervention, his needs, what satisfies him, within what is possible, but also in respect to his rights (H06).

The same mental healthcare provider also intervened more than home care program healthcare providers regarding social activities:

> What I wanted to see with him was the opportunity to volunteer. We try to see what can be offered in the community, not just from the HSSC. Participation or integration has to happen in the community (H06).

Moreover, the perceived high cost of assistive devices and some private or community resources limits their use by older adults and caregivers who often have limited financial resources:

> Her financial resources are not such that she can afford to say, 'I'll hire someone who will come two or three times a week.' I know she has already asked for it, but because of finances she was forced to stop (C03; Table I).

Older adults and their caregivers were also sometimes suspicious of the use of interventions outside the public system: "[…] they have a fear of people they do not know, fear of being robbed" (H01).

Older adults and caregivers had varied and limited comprehension and openness with regard to interventions that were available to them:

> Difficulty observed assimilating the information given by a healthcare professional. Does not write information on paper to ask the doctor any questions, despite the recommendations […] Not open to professional recommendations (notes in file 03).

Despite a contraindication to receive physiotherapy for his spasms, interview with the older adult reveals that his understanding of the situation is different: "[…] as they answer it isn't worth it […] but it would help a lot. It is very difficult to make them understand whatsoever" (O03). Another older adult did not feel she was understood by her healthcare provider about bathing: "I've asked many times, but you know when you ask a man, he sees no need. […] Before […] I used to fully bathe, every day" (O01). The older adults sometimes had to deal with the prejudices of people who were helping them, as was the case for a senior with a mental illness living in a family-type residence regarding his participation in meal preparation: "We are not allowed (cooking), no one participates in it here. Residents lack cleanliness. He would not know how to (cook)" (C06). This attitude prevents older adults from participating: "This home has a lot of overprotection" (H06).

In addition, older adults, caregivers and healthcare providers had limited empowerment and knowledge about interventions and available resources in home care services and community organizations, including procedures to receive these interventions:

> If there are places where I could get two or three hours a day, where he could work with supervision from someone […] it would fill his day. But I do not know of any places where he could do that (C07; Tables I and III).

There was even limited understanding of the HSSC's mandate:

> I was not even aware that she was entitled to the HSSC, I found out by chance. It's like total nothingness, where to go for that (someone to socialize with). It will not be the HSSC that takes care of it because the HSSC handles, in my opinion, mental and physical health (C03).

In many cases, healthcare providers forgot that community resources could meet some of the older adults' needs. "The resources in the community, I had not thought of that, but yes, it could be good" (H01). Healthcare providers sometimes left the older adult a list of available resources, but rarely took time to discuss them or to assist the senior in using these resources. "I guess I left the small sheet with community organizations on the back side of the page" (H04). Even certain home primary care interventions were sometimes overlooked by healthcare providers. "I don't know much about the day center, but for the moment I do not think he is a candidate for it. I don't know […]" (H04). However, the day center provided social activities for some older participants and offered physical and cognitive exercises: "It's good what they do. They help to make us participate in all sorts of things, exercise flexibility and memory" (O10). For some, the day center allowed both the creation of meaningful activities and provided respite to the caregiver:

> She loves the day center, it's really important to her. It is her weekly outing, and she also knows that it is a moment for her husband (caregiver) to take care of himself (H01).

Finally, several caregivers openly discussed their involvement and, for some, their feeling of exhaustion:

> I had to let go because of the mental and physical strain. They (the parents) will ask for a lot, a lot, a lot, that's why I had to let go because, otherwise, I would have been the sick one (C03).

Few interventions were available to help caregivers meet the needs of older adults and prevent burnout, for example, through support and respite. "So, I have two people to take care of while someone should take care of me. I do not understand why caregivers are not entitled to anything" (C02).

Discussion

This study aimed to explore the match between needs and interventions enabling participation of frail older adults who receive services from a home care program in the public healthcare system. Results indicate that the interventions offered focus on security and independence in personal care, dressing, mobility outside the home and meal preparation, but do not fully meet the needs of older adults in relation to these dimensions. Unmet needs concern mainly social activities (responsibilities, interpersonal relationships, community life and leisure) and some daily activities (fitness, housing and mobility outside the home). These results are in agreement with those of other studies (Talbot *et al.*, 2004; Markle-Reid *et al.*, 2008) and raise several questions regarding the HSSC's responsibilities for the health and well-being of the population in its territory. Given that the benefits of community integration have been clearly demonstrated, this discrepancy between needs and interventions enabling participation is troublesome. Indeed, as it has been shown that doing daily activities is less associated with quality of life than doing social activities (Levasseur *et al.*, 2008), the interventions currently available to older adults do not optimally promote their well-being. The importance of considering more meaningful activities, inner life (e.g. life experiences; concerns; and feelings of control, freedom and feeling appreciated) and adaptation (Levasseur *et al.*, 2009) should also be highlighted. Volunteering, for example, is an opportunity to maintain or create a sense of belonging to a group and to ensure that older adults participate in the social fabric (Sevigny and Vezina, 2007). For instance, a friendly phone call or visit from a volunteer is not only a service, an individual contact, but it is also a way to preserve the link with society. Leisure and social activities are also often wrongly seen as a luxury, as they allow older adults to live not only longer but also more fully. Indeed, the benefits of participation in social activities are numerous and well-documented in the scientific literature. These benefits include reduction in mortality (Maier and Klumb, 2005; Zunzunegui *et al.*, 2003), slower cognitive (Zunzunegui *et al.*, 2003) and functional (Avlund *et al.*, 2004) decline, decreased drug use (Bath and Gardiner, 2005), reduced use of health services (Bath and Gardiner, 2005), improved perceived health (Bennett, 2005), reduction in depressive symptoms (Abu-Rayya, 2006) and increased sense of well-being (Van Willigen, 2000).

Interventions offered by the HSSC's home care program are clearly insufficient (Hébert, 2012) and the HSSCs do not fulfill their new responsibilities to meet older adults' needs for social activities and to work with partners in the local area network, including community organizations, to actively ensure that efforts are made to maintain and improve their health and well-being. Although a significant budget increase allocated to home care is required (Hébert, 2012), a simultaneous substantial change in clinical

practice is also mandatory, including offering broader interventions (Raymond *et al.*, 2013), establishing real partnerships with community organizations and thoroughly covering social activities in the systematic assessment of older adults' needs. To allow a significant investment in home care, local government must review its current use of budgets and tax credits and could establish an allowance for autonomy support, the amount of which would be established following an evaluation of the person (Hébert, 2012). A more comprehensive assessment of participation needs, however, must accompany this allocation. Indeed, the assessment tools currently used by healthcare providers do not allow them to properly identify psychosocial needs (Delli-Colli *et al.*, 2007), including doing meaningful activities and leisure, and community integration. In addition, private and community resources should receive greater recognition as indispensable partners. It is important to ask if in reality, community organizations' finances allow them to support their HSSC, including their populational responsibility to promote community integration of older adults.

Finally, it is also important to ask about the power or empowerment of frail older adults and their caregivers, mainly in relation to the HSSC. The results of this study indicate that older adults and their caregivers are not sufficiently informed about available interventions enabling better participation. Most of them might not know how they can influence the allocation of services (participation in Users' Committees; representation on institutions' boards of directors; Complaints Commissioner: legal remedies under the right of access; involvement in organizations defending their rights and access to services). From a legal perspective, the findings from this study call into question the right of access to services, distributive justice (distribution of resources according to social solidarity) and the quality of services (Carrier *et al.*, 2010). The information regarding interventions and resources provided to older adults and their families must also be optimized. Older adults and their caregivers should be more involved and accompanied by effective collaboration and partnership in identifying their needs and implementing the interventions. It is important to go beyond their complaints and demands, and respect and promote their desire for autonomy and independence. Using a tool for facilitating older adults' goal setting to structure interventions to assist them in the home (Parsons and Parsons, 2012) and to integrate the assessment procedure has been demonstrated as a driver for quality improvement in home care, especially for preventive services (Brown *et al.*, 2009). Moreover, when compared with usual care, restorative home care interventions, i.e. helping service users to regain confidence and re-learn the skills necessary for daily living to maximize their independence, can improve older adults' health-related quality of life over time (King *et al.*, 2012). Finally, caregivers must be recognized as indispensable partners rather than resources (Hébert, 2012), to whom it is important to provide support and respite.

Strengths and limitations of the study

The various contributors from different fields of expertise provided a broad vision of the participation of frail older adults. The plurality of the data sources and the diversity of the participants interviewed allowed triangulation of the data, rich data and good internal validity (Laperrière, 1997). Social desirability, a potential bias, was minimized by providing a detailed explanation of the research objectives and reassuring participants that there were no right or wrong answers. A limitation of the study was the inclusion of a single HSSC and a limited number of older adults, caregivers and healthcare providers.

Future studies

To pursue optimization of the match between needs and services for participation of older adults, more studies are warranted. Among the promising avenues, using a participatory research design, it is important to improve the partnerships between the HSSC and community organizations. In addition, such research works might also aim at increasing the knowledge of healthcare providers on comprehensive assessments and goal setting reflecting participation needs of older adults, especially social activities. Increasing knowledge on interventions available in the community through innovative ways is also of interest for future studies. More research on the effectiveness of personalized community integration (Lefebvre, 2012) interventions is required to enable older adults having disabilities to carry out activities that are meaningful and important to them, that they find problematic to realize or that they wish to pursue. Finally, accompanying a change in the current role of healthcare providers working in home care programs is required to fulfill their health promotion responsibilities, especially regarding promotion of social and leisure activities.

Conclusion

Improving or maintaining older adults' participation is the ultimate goal of social and health interventions. This research has deepened our understanding of the fit and the challenges in reducing the discrepancy between needs and interventions enabling participation of frail older adults who receive home care services. To improve and maintain it, participation should be assessed more comprehensively, including social activities more specifically. Also, more support should be provided to older adults and their families regarding the use of resources. It is also important to review the services offered by HSSCs (primary care services) and optimize partnerships with community organizations. Thus it is possible to further improve and maintain participation and quality of life of frail older adults living at home.

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Further reading

Constitution Act 1867. 30 & 31 Victoria, c. 3

Appendix

Table AI shows identifying and defining key areas of participation in the disability creation process model 1 and identifying interventions linked to these dimensions and key players.

About the authors

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Noémie Royer is an Occupational Therapist at the Health and Social Services Centre of the University Institute of Geriatrics of Sherbrooke working with older people with various health conditions. She just completed her master's degree in occupational therapy in April 2013 at the Université de Sherbrooke. Noémie has a great interest in research, particularly in the field of health promotion. During her studies, she worked two summers as a Research Assistant. Although she is now a clinician, she continues to be involved in various research projects.

Johanne Desrosiers is a Professor, Director and Vice Dean of Rehabilitation in the School of Rehabilitation of the Faculty of Medicine and Health Sciences of the Université de Sherbrooke. She is also a researcher at the Research Centre on Aging, Health and Social Services Centre of the University Institute of Geriatrics of Sherbrooke. She has been an occupational therapist since 1979, and graduated from the Université de Montréal. After ten years of professional clinical

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Philippe Landreville, PhD, is a Psychologist and Full Professor of Psychology at Université Laval in Québec City. He is currently a researcher at the Research Centre of the Centre hospitalier universitaire (CHU) de Québec. He is a specialist in the clinical psychology of older people. His research interests include behavioral and psychological symptoms of dementia, mood and anxiety disorders in older adults.

Philippe Voyer, RN, PhD, is a Full Professor in the Faculty of Nursing Sciences at Université Laval in Québec City, and a Researcher in the Research Unit of the Centre for Excellence in Aging in Québec City. He has been a Professor in the Faculty of Nursing Sciences at Université Laval for the past 13 years and teaches geriatric nursing to student nurses at the undergraduate and graduate levels. His graduate students have conducted studies on delirium, behavioral problems among patients with dementia and the use of psychotropic medication by older people. Voyer is also a researcher attached to the Québec Research Network on Aging (RQRV.com) and leads projects on delirium among older patients in acute and long-term care settings. In the Québec Research Network on Aging, Voyer has been responsible for the assessment of clinical practices in long-term care units for eight years (2004-2012). As a geriatric nurse specialist, he devotes 10 per cent of his time on a weekly basis to providing direct care to older people.

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Andrée Sévigny is a Social Worker and an Associate Professor in the Department of Family and Emergency Medecine at Université Laval. She is a Researcher at the Centre d'excellence sur le vieillissement de Québec (CEVQ) and Assistant Director of the Institut sur la participation sociale des aînés at Université Laval. Sévigny completed a PhD in social work at Université Laval as well as two post-doctoral research projects. The first, financed by a CIHR training grant, concerned palliative care and included a six-month internship at the Research Centre in Médecine, Sciences, Santé et Société (CERMES), associated with the CNRS, INSERM and ÉHESS in France. This internship explored qualitative methodology and the theoretical foundations of health practices. It included a multisite research project carried out in three Canadian provinces (Québec, British Columbia and Alberta). The second post-doctoral project, financed by a CIHR-FORMSAV grant (2005-2006), explored volunteering done by older people for older people receiving home palliative care. Sévigny's research program focuses on the social participation of the older population, more specifically on the volunteer work done in the homes of frail older people or for those receiving end-of-life care.

Dimensions of social participation	Definitions	Examples of possible interventions (key players)
Daily activities		
Nutrition	Habits related to food consumption (habits related to choosing foods, food preparation, preparing meals, etc.)	Information and evaluation of food and nutrition (HSSC) Home delivered meals (Meals on Wheels; Sercovie) Human Assistance (Cooperative Home Care, Alliance for AAL; Community Help, caregivers support service, volunteers)
Fitness	Habits related to fitness of body and mind (habits related to sleep, naps, physical and mental fitness, etc.)	Medical services (HSSC) Human Assistance (HSSC; PersonnAide; caregivers) Physical and calming activities (Day Centre, Sercovie; Rayon de Soleil)
Personal care	Habits related to physical well-being (hygiene, excretory hygiene, dressing, health care)	Services provided by nurses and occupational therapists (HSSC) Info-santé (HSSC) Human assistance (HSSC; Alliance for Home Support; PersonnAide Foundation; caregivers) Pharmaceutical services (HSSC; Pharmacies)
Communication	Habits that enable a person to exchange messages with others (oral, sign and written communication; telecommunication)	Human assistance (Alliance for Home Support; caregivers) Rehabilitation services (HSSC) Equipment loan (HSSC; Day Center)
Housing	Habits related to individual's place of residence (lodging, home maintenance, use of furnishing and other household appliances)	Adaptation of the housing (HSSC) Housing needs Services related to maintenance (HSSC via service employment check; Cooperative Home Care; Alliance for Home Support; PersonnAide; caregivers)
Mobility	Habits related to mobility over short and long distances with or without means of transportation (using means of transportation, generally within the immediate environment, such as walking, car, etc.)	Rehabilitation services (HSSC) Equipment loan (HSSC) Adapted transportation Accompaniment transport network (friends, community help, volunteer services) Human assistance (Network of friends; caregivers)
Social roles		
Responsibilities	Habits related to taking up responsibilities (habits related to financial, civil and family responsibilities, such as preparing and following a budget, respect for others and civic responsibility, and the care of a person, such as children, spouses, etc.)	Help with financial planning (budget solution; caregivers) Accompaniment transportation (Network of friends, caregivers) Promotion and advocacy (Association québécoise de défense des droits des personnes retraitées et des préretraitées; Fédération des âges d'or du Québec; Association des grands-parents du Québec)

(*continued*)

Table AI.
Identifying and defining key areas of participation in the Disability Creation Process model 1 and identifying interventions linked to these dimensions and key players

Dimensions of social participation	Definitions	Examples of possible interventions (key players)
Interpersonal relationships	Habits concerning relationships with others (habits concerning sexual activity between people, affective relationships with family, friends, people in individual's surroundings)	Individual and couple psychosocial support, family or groups (HSSC) Friendly visits, phone calls, outings, support groups, telephone support (Network of friends; Alzheimer Society; Sercovie; Alliance for AAL, The Little Brothers of Poor Sunbeam; Day Center, community services, support services; caregivers)
Community life	Habits related to activities within the community (participating in social organizations, such as social clubs, and participating in spiritual life and religious practice)	Equipment loan (HSSC) Accompaniment-transport (Network of friends, Coopérative de services à domicile, Alliance pour l'autonomie à domicile; caregivers)
Education	Habits related to individual psychomotor, intellectual, social and cultural development (participating in a training program, etc.)	University of Third Age and CursUS Health (University) Training and information on various topics (e.g., health, IT, Alzheimer's disease, abuse) (HSSC, Alzheimer' Society; Sercovie, Association for information and training against elder abuse; Rayon de soleil)
Employment	Habits related to the principal occupation of the adult individual; usually a paid occupation (volunteering)	Involvement in various community organizations (Trav-action, Volunteer)
Leisure	Habits related to recreational activities or others practised in one's free time and in a pleasurable context (sports and games, arts and culture, and socio-recreational activities)	Varied and adapted activities (Day Centre; Sercovie; Rayon de soleil; community services) University of Third Age and CursUs Health (University) Friendly visits, group outings (network of friends; Alzheimer Society; Sercovie; Alliance for AAL; community services, support services, caregivers

Table AI.